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Attitudes towards epilepsy in the UK population: results from a 2018 national survey

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Abstract

Purpose: To measure stigma resulting from negative attitudes toward epilepsy in the United Kingdom (UK) population.

Methods: An online survey of a stratified quota sample of UK adults in July 2018. The primary outcome measure was the 46-item Attitudes and Beliefs about Living with Epilepsy (ABLE) scale, scored on a five-point Likert scale. Items on sociodemographic characteristics, experience of epilepsy, and knowledge of epilepsy were also included. Mean scores were calculated for the ABLE and subscales: risk and safety concerns, personal fear and social avoidance, work and role expectations, and negative stereotypes. Hierarchical regressions tested the association between mean ABLE and subscale scores with sociodemographic and epilepsy related factors.

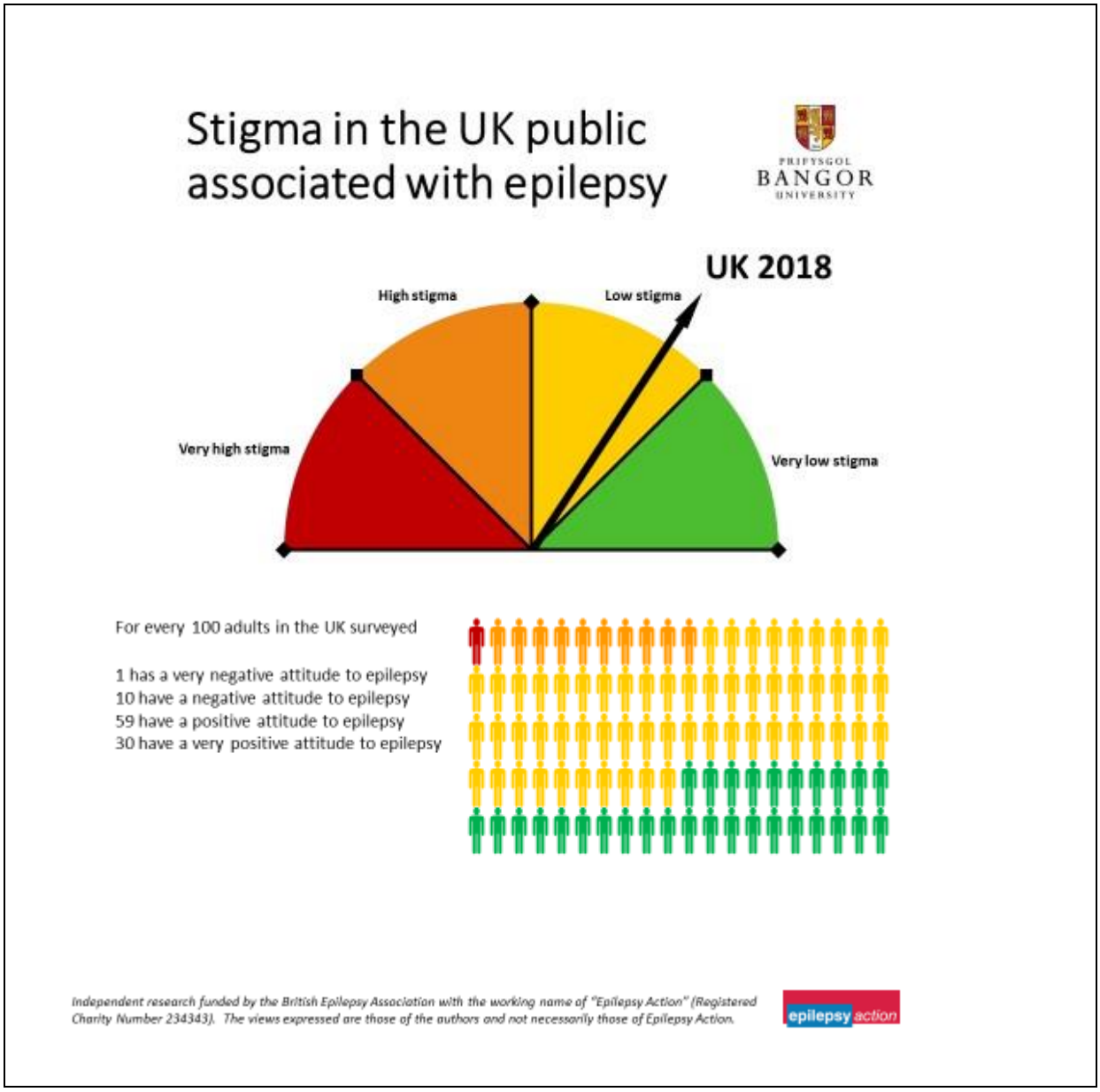
Results: 4,000 responded, 3875 responses were included in the analysis. Mean ABLE score was 2.28 (95% CI: 2.26-2.29) (1=no stigma, 5=high stigma). Subscales: risk and safety concerns 3.22 (95% CI: 3.20-3.25), personal fear and social avoidance 2.13 (95% CI: 2.11-2.16), work and role expectations 2.07 (95% CI: 2.05-2.09), and negative stereotypes 1.67 (95% CI: 1.65-1.69). Mean knowledge score was 78% (95% CI: 76.15-77.02).

Conclusion: Findings of the first UK national survey of attitudes and beliefs about living with epilepsy suggest relatively low stigma among the sampled population. The subscale with the least stigma was negative stereotypes. Risk and safety concerns were associated with highest stigma. Improving public knowledge about epilepsy has potential to reduce stigma, however this may also raise risk and safety concerns. The results from this project could inform future work to improve awareness and understanding of epilepsy.

Keywords:

Epilepsy, attitude, belief, stigma, survey, UK

Graphical Abstract



Introduction

Epilepsy is a common chronic neurological condition affecting at least 50 million people globally [1]. People with epilepsy often experience stigma and discrimination because of the condition and as such, their social and personal expectations are often restricted[2]. The experience of stigma may even affect their quality of life even more than the medical condition itself[3]. Where people with epilepsy feel prevented from living an ordinary life due to stigma resulting from negative attitudes, this may be an internal perception rather than widely enacted discrimination[4]. It is important to understand any stigma that people with epilepsy may face. This may help to improve quality of life for people with epilepsy.

One in 103 people in the United Kingdom (UK) are living with epilepsy[5] yet little is known about the UK public attitude towards epilepsy and people with epilepsy. Research to date, has predominantly focused on experience of stigma by people with epilepsy; and, evidence of the associated negative attitude in society is more limited. Researchers in the United States (US) developed the Attitudes and Beliefs about Living with Epilepsy (ABLE) scale to measure public attitudes to epilepsy and people with epilepsy[6,7] and have used this longitudinally to measure changes in public perceptions[8]. Tracking public attitudes over time has potential to assist patient organisations, such as Epilepsy Action in the UK, plan future work to improve awareness and understanding of epilepsy and to evaluate the success of such campaigns. Evidence on public attitudes may also contribute to the debate on internal perceptions of stigma. Consequently, creating, strengthening and implementing policies to promote access to information and knowledge may help reduce the stigma surrounding people living with epilepsy.

The aim of our current study was to quantitatively assess public attitudes to epilepsy and people with epilepsy in the UK in 2018. Specific objectives were to (i) measure public attitudes to epilepsy and people with epilepsy in the UK using the ABLE scale[6,7,8] by assessing levels of stigma related to: risk and safety concerns, personal fear and social avoidance, work and role expectations, and negative stereotypes. (ii) measure associations between stigma and sociodemographic characteristics, experience of epilepsy, and knowledge of epilepsy. We hypothesised that attitude would vary by age, gender, ethnicity, and education, consistent with previous findings[6]. We also hypothesised that people with experience of epilepsy (self or other) and/or higher knowledge of epilepsy would demonstrate less stigma.

Methods

Study design

A cross-sectional web-based survey was conducted in the UK on a nationally representative sample of adults aged 18 or over. . All data were collected in July 2018. The study was approved by Bangor University Healthcare and Medical Sciences Academic Ethics Committee. The study was conducted and reported according the STROBE checklist for cross-sectional studies [9]. All data were analysed in STATA 13 (StataCorp LLC, College Station, TX).

Participants

Members of the public were recruited using a consumer marketing panel. The panel is made up of pre-recruited members of the public who have agreed to participate in online surveys. The company used quota sampling to achieve a sample that was representative of the UK public, stratified by age, gender, region and socioeconomic group. Respondents were required to check a series of boxes to confirm that they had read and understood the participant information before proceeding to the questionnaire. The

participant information contained details relating to the survey (e.g. length of time to complete) and participation (e.g. that participants may withdraw at any stage, confidentiality etc.). Respondents were incentivised to participate by collecting points, tradable for goods (equivalent to £0.17).

Outcomes

The primary outcome measure was the ABLE scale[6]. The ABLE scale contains 46-items to measure stigma associated with epilepsy, in the general public. Twenty-three items assess cognitive beliefs about people with epilepsy, which include items describing characteristics of a person with epilepsy, and the abilities and limitations of people with epilepsy. Thirteen items assess affective reactions towards people with epilepsy (e.g. discomfort, shame, fear, pity). Ten items assess respondent intentions toward social distancing behaviours (e.g., would be nervous around a person with epilepsy because she or he might have a seizure). All 46-items were included in the survey, assessed on a five point Likert scale ranging from strongly disagree to strongly agree[8], the underlying construct of each item varied in terms of whether they were positively or negatively phrased. Secondary outcomes were four subscales, constructed from items within the ABLE, that measure difference stigma domains: risk and safety concerns (6-items), personal fear and social avoidance (8-items), work and role expectations (8 items), and negative stereotypes (7 items).

The research team assessed the US version of the ABLE for UK language specificity. Five items were adapted by replacing terms that had a direct equivalent in the UK (i.e. elementary school was replaced to primary school), otherwise, by providing further explanation in parentheses alongside the original US wording.

Additionally, questions were included to measure personal experience of epilepsy, attitude towards epilepsy, knowledge about epilepsy, and sociodemographic characteristics. In addition to the stratification variables of age, gender, region and socioeconomic class, sociodemographic factors included ethnicity, employment status, education level, experience of marriage/civil partnership, having children, and annual household income. A purposive review of epilepsy knowledge and experience measures was conducted to determine items for inclusion in the questionnaire. The final questionnaire contained 4-items on experience of epilepsy (self or other) and witness of seizures. As the purpose was to assess whether the respondent had witnessed a seizure in real life, rather than on TV, this question was phrased *"Have you ever seen someone have a seizure in person?"*. Respondent's knowledge about epilepsy, was tested using 15 true or false items and 1 multiple choice question adapted from the Epilepsy Knowledge Profile-General[10,11]. This section was specifically designed to assess knowledge of the condition and its symptoms, characteristics, prevalence and treatment. Responses to each question were mandatory to progress to the next item.

A pilot study was conducted in a convenience sample of 22 members of Bangor University and Epilepsy Action employees. Twelve people completed the questionnaire and provided feedback on completion time and comprehension of items. The mean completion time of the pilot questionnaire was 12 minutes. In response to the pilot feedback, one ABLE item was rephrased, and knowledge questions were refined. Overall, participants were asked to complete a maximum of 77 questions.

Study sample

The minimum sample size was defined as 2,401 responses, based on a 95% confidence level, an assumed standard deviation in ABLE score of 1.25, and a confidence interval width of 0.1[12].

To allow for analysis of multiple subgroups and to allow for potential irrational responders to be removed, 4,000 responses were collected

Representativeness of the sample was assessed for the stratification variables, and socio demographic characteristics by comparing participant responses with data for the general UK population[13]. Response bias was assessed by identifying non-differentiation (straight lining) and inconsistency in responses[14]. Nondifferentiation occurs when respondents give identical answers to all items. Given the nature of the design of the ABLE, with the direction of the underlying construct being reversed in over 40% of questions, we considered a participant to be non-differentiating when they provided the same response to over 41 (90%) of the questions within the ABLE. It was not possible to assess sample bias or self-selection bias, as the required data was not available from the consumer marketing panel.

Analysis of primary outcome

Each item from the ABLE questionnaire was scored on a five-point Likert scale ranging from strongly disagree to strongly agree, consistent with the most recent US application[8]. Twenty- seven items were reversed so that positively and negatively worded items were scored in the same direction as the underlying scale construct. Thereafter, higher scores indicated more negative attitudes towards a person with epilepsy[6]. On review of the responses and in consultation with Epilepsy Action, scoring of a further item, *"I believe people with epilepsy cannot have as good quality of life as people without epilepsy"* was also reversed.

Mean score and 95% confidence intervals were generated for the ABLE scale (46-items) and four subscales. Chronbach Alpha was reported as a measure of internal consistency for each scale.

Analysis of sociodemographic, experience and knowledge items

Frequencies and descriptive statistics were reported for demographic items and experience of epilepsy. Subgroup analyses, using t-tests and ANOVAs were conducted to describe differences in responses according to respondent characteristics. Items on knowledge were scored and summed such that higher scores indicate a higher level of knowledge. Knowledge score was reported as a percentage of items answered correctly. Association between actual knowledge (knowledge test score) and the ABLE item "*I believe I know a lot about epilepsy*" was compared descriptively. Due to multiple comparisons resulting in an increased risk of a false positive result, significant results were conservatively reported at $p<0.001$, following Bonferroni correction.

Regression analysis

Hierarchical regression was used to adjust for any confounders, and assess how sociodemographic characteristics, experience and knowledge were able to explain stigma, multivariately. Responses of "*unknown*" or "*prefer not to say*" were treated as missing in the regression. Regression analyses were performed for the ABLE scale, and each subscale.

Results

Four thousand responses were received and examined for eligibility. All responses were complete, with no missing data. One-hundred and twenty-five respondents were excluded from analysis due to nondifferentiation, the remaining 3875 were included in the analysis.

Descriptive data: Demographics

The mean age of the sample was 49 years (range 18 to 92). Sample demographics (Table 1) were representative of the UK general public with our sample falling within 3% of UK proportions for each of the stratification variables. One-hundred and eighty-nine people with epilepsy or a seizure disorder completed the survey; which is higher than estimates based on UK prevalence of epilepsy alone. Less than half the sample knew someone with epilepsy, most commonly a friend or family member. Just over half had witnessed a seizure in their lifetime; one in four had witnessed a seizure within the last 5-years.

Outcome data: ABLE scale

The population mean for the 46-item ABLE scale questions was 2.28 (95% CI:2.26-2.29) (Table 2). When considering the mean scores of each of the 3875 respondents, 5 (<1%) have a very negative attitude to epilepsy (ABLE score 4+), 396 (10%) have a negative attitude to epilepsy (ABLE score between 3&3.9), 2317 (59%) have a positive attitude to epilepsy (ABLE score between 2&2.9), and 1157 (30%) have a very positive attitude to epilepsy (ABLE score less than 2). Our findings therefore suggest that the average person in the UK has a somewhat positive attitude toward epilepsy, in that they agree (but do not strongly agree) with positive statements. Items from the ABLE scale showed very good internal consistency, (Chronbach alpha 0.94), consistent with DiIorio and colleagues[6].

Mean scores for individual items suggest that seven items were associated with a negative attitude (supplementary material 1; score >3 in Table 2). Items associated with the most negative attitude were "*I believe I know a lot about epilepsy*" (57% disagreed with this statement) and "*I would let my child ride in a car with a driver who has epilepsy*" (50% disagreed with this statement). In general, respondents expressed a level of agreement or disagreement to each item, there were only 9 items where the modal response category was *"uncertain"*. "*I believe people with epilepsy can safely operate heavy machinery*" had a mean score of 3 (95%CI:2.97-3.03), with 42% of respondents selecting the *"uncertain"* option, suggesting the average person in the UK is uncertain of their opinion on this.

Subscales

Internal consistency was "*good*" or better for all four subscales (Table 2). The highest score was on the risk and safety concerns domain (mean=3.22, 95%CI: 3.20-3.25). Among the items describing risk and safety concerns, four had average scores that indicated negative responses (mean item score >3). All four of these items were associated with driving and/or children. Among the items in the personal fear and social avoidance subscale (mean 2.13, 95%CI: 2.11-2.16) the majority of respondents indicated they would not be embarrassed if someone in their family had epilepsy. A lower score on the work and role expectations subscale (mean 2.07, 95% CI: 2.05-2.09), indicated a perceived work normality for people with epilepsy. The negative stereotypes subscale had the least negativity of all subscales (mean 1.67, 95% CI: 1.65-1.69), indicating that negative stereotyping is relatively low in the UK. All seven items in this subscale had mean scores that indicated agreement with positive statements, or disagreement with negative statements.

Epilepsy knowledge

Percentages of people responding correctly to each of the knowledge items are listed in table 3. The mean overall knowledge score was 77% (95% CI: 76.15-77.02). Less than half of respondents responded correctly to questions on prevalence, seizure first-aid, and epilepsy manifestations. Most people were aware that epilepsy is not contagious (92%). A quarter of respondents did not know that

people with epilepsy are protected by the Equality Act. We explored association between actual knowledge and the ABLE item "*I believe I know a lot about epilepsy*". Perceived knowledge (ABLE item "*I believe I know a lot about epilepsy*") negatively predicted actual knowledge (knowledge test score). People who strongly agreed with the ABLE statement had a lower mean knowledge test score (68%).

Subgroup analysis

Univariate, statistically significant differences in mean attitude and subscale scores were identified for gender, employment, marriage, children, people with epilepsy, people who knew someone with epilepsy, and witnesses of seizure (Table 4).

Using ANOVA, statistically significant differences in attitude between age categories were observed for all scales ($p \leq 0.001$) (Figure 1). Men had attitudes that are more negative on all scales, with the exception of risk and safely concerns. People in employment had significantly lower risk and safety concerns but more fear and social avoidance, and negative stereotyping, compared to people not in paid employment. Risk and safety concerns were also lower for respondents who had never been married or in a civil partnership and respondents with children.

People with epilepsy had significantly lower risk and safety concerns, but significantly higher scores (were more negative) on all other subscales, compared to people who do not have epilepsy. Whereas, people who knew someone with epilepsy had significantly higher risk and safety concerns, more personal fear and social avoidance, and more negative work and role expectations, than people who did not know anyone with epilepsy. Those who had witnessed a seizure had significantly less negativity on all domains other than negative stereotypes, but both groups had low stigma on this domain.

Despite reaching statistical significance, the actual difference in mean score between groups was quite small and explained a limited amount of the variance in stigma (less than 5%).

Hierarchical regression

The results of the regression between attitude towards epilepsy and other factors are summarised in table 5, for the full ABLE scale and subscales. Multivariate results were largely consistent with univariate results (subgroup analyses). Overall, more negative attitudes were significantly associated with sociodemographic factors (age <35 or >65, male), experience of epilepsy (not knowing a person with epilepsy, never having witnessed a seizure) and having lower epilepsy knowledge. Experience of epilepsy was the greatest contributor to risk and safety concerns, interestingly, people with epilepsy had significantly lower risk and safety concerns.

These models explained a limited amount of the variance in attitude (between 8% and 48%). The ABLE scale model explains 35% of the variance in attitude. The sociodemographic factors entered into the regression model explained 9%, experience factors explain a further 2%, and adding knowledge about epilepsy explained a further 25%. Across subscales sociodemographic explained no more than 14% of the variance around the score, and experience added no more than 4%. Knowledge was the largest contributor, in all models except risk and safety concerns. Ranking of individual knowledge factors within the regression analyses are presented in Table 3. Lower knowledge of the most commonly known items appears to predict more negative attitude, with the exception of the risk and safety concerns

domain, where higher knowledge of three items was associated with higher concerns (epilepsy is not contagious; seizure types vary; and you cannot tell by looking at someone with they have epilepsy).

Discussion

Key results

Stigma toward epilepsy and people with epilepsy was present among the sampled UK population, however the findings suggests the attitude of the average person is associated with relatively low stigma. Attitudes differed by subscales. The least negative subscale was negative stereotypes, suggesting that the average respondent disagreed or strongly disagreed with statements on negative stereotypes. Risk and safety concerns were associated with the most stigma.

Sociodemographic and experience factors explain a limited proportion of the variance in stigma score and across domains. Knowledge factors contributed the most explanation of negative attitude, however, the direction of effect varied. Overall, lower knowledge was associated with more negative attitude, with the exception of risk and safety concerns, where higher knowledge in some areas was associated with higher concerns.

Interpretation

Reducing stigma is a major activity of patient support groups globally[15]. Epilepsy Action, in the UK, has a goal to improve awareness and understanding of epilepsy and our findings suggest that this has the potential to reduce stigma. In the current study, 95% of the population scored between 44-100% on the knowledge test. Less than half the people surveyed were aware of how many people are living with epilepsy in the UK, knew how to respond when someone was having a seizure, or, understood that seizures can have different triggers. Only a quarter of respondents were aware that people with epilepsy are protected by the Equality Act, which may also allude to a lack of understanding about the classification of disability under this act. Whilst 20% of people believed they knew a lot about epilepsy, of interest was that respondents who believed they knew a lot about epilepsy had a significantly lower knowledge score. Researchers in other fields have suggested that individuals who express a belief that they are more knowledgeable and may have a perception that they are better informed, despite displaying higher evidence gaps between their perceived and actual knowledge[16]. This finding warrants further research in the context of epilepsy.

When assessing the relationship between stigma and knowledge, an incorrect response to the most commonly known items was associated with greatest stigma; this suggests that increasing the knowledge of this minority may have the greatest impact. Association between attitude and knowledge reversed on some items in the risk and safety domain, suggesting that higher knowledge was associated with being more risk averse. Furthermore, the most negative finding on work and role expectations, related to safety – which concurs with the findings of the risk and safety are of highest concern to the UK public. Future agendas should therefore focus on both improving knowledge, addressing risk and safety concerns, and dispelling misconceptions.

Stigma in the UK was found to be relatively low, with ~90% of the UK public having a neutral to positive attitude. This evidence may contribute towards the debate on internal perceptions and enacted stigma. Whilst the concepts of perceived and enacted stigma represent different constructs, targets for intervention may share some common ground. In the UK, Taylor and colleagues reported that 54% of people with newly diagnosed epilepsy (n=1566) indicated feeling stigmatised; and, that reduced mastery, younger age (<50), and seizures frequency, were amongst factors significantly associated with

this feeling [17]. A recent systematic review of 25 quantitative studies of correlates of stigma in epilepsy, also found that stigma was associated with demographic, illness-related, and psychological factors; and, that these associations were highly culturally specific[18]. This suggests that campaigns targeting factors associated with public attitudes and knowledge, may also have a positive impact on people with epilepsy. Furthermore, previous research has demonstrated the benefits of people with epilepsy themselves being involved target audience-directed content and mode of delivery[19]. This warrants further exploration in the interpretation of the current findings and development of future campaigns.

Comparison with other studies

To our knowledge or study is the first application of the ABLE scale in the UK. A review of the literature identified four studies reporting the results of the ABLE scale[6,7,8,20]. Direct comparison across all studies is not possible, due to heterogeneity in Likert scales[6,7], subscale content[20], and population. The findings of this study, however, can be compared with US public attitudes on fear and social avoidance, where the US public were found to be slightly more negative (2.18 versus 2.13)[8]. Our results also follows the general trend of previous studies, in that risk and safety concerns are associated with the most stigma, and negative stereotypes are associated with the least stigma. Health-related stigma has been measured for several other conditions, for example HIV/AIDS, leprosy, tuberculosis, mental health, obesity[21,22,23,24]. The literature suggests that the consequences of stigma being remarkably similar between conditions and cultures, however, instruments to measure stigma tend to be condition specific[24]. The Time to Change anti-stigma campaign in mental-illness-related public sigma among the English population[25] is based on the "Attitudes to Mental Illness" national survey. This includes 26 attitude items derived from the Community attitudes toward the Mentally Ill scales and an additional item on employment-related attitudes. There are two subscales: prejudice and exclusion, and tolerance and support; in this case higher scores indicate more positive attitudes. Attitudes to mental illness in the English population in 2013 were in the region of 3.9 to 4.0, where 5.0 is positive[25]. When compared to our findings of epilepsy stigma in the UK, the levels appear to be in the same region (2.1 to 2.0 when scaled in the direction of 1.0 being the most positive).

Strengths

Our study has several key strengths. Firstly, we surveyed a large sample of the UK general population, representative of age, gender, region and socioeconomic group. Secondly, our analysis considered the distinction between what could predict negative attitude across all of the stigma domains (subscales). Thirdly, we considered the contribution of distal and more proximal factors associated with attitude (e.g. sociodemographic, experience and knowledge). Finally, we conducted further exploratory analysis on more modifiable factors such as knowledge. Our consideration of perceived and actual knowledge also gave insight to both the need to improve knowledge and address potential misconceptions.

Limitations

There are several limitations to our analysis. Firstly, our study used quota sample, we must therefore acknowledge the risk of selection bias. The survey was administered online, via a consumer marketing panel which may influence the results insofar as only people who were actively interested in completing web-based surveys participated, which may reduce the external validity of our findings. Review of our stratification variables confirmed that our sample was representative of the UK general population in terms of age, gender, region, and socioeconomic class; and our approach to sampling was balanced against efficient data collection. Secondly, a pragmatic approach was taken to assessing rational responses, as with all surveys there is potential for false responses. Thirdly, sociodemographic groupings used in the regression models were often broad (e.g. ethnic group), therefore, we cannot make

any inferences on any specific categories within groups, which may be associated with attitudes that are more negative. Finally, the ABLE instrument was developed using attitudes of the US population in 2002[6]. We identified six ABLE-items that required changes to reflect UK English language; we also recoded a single item to represent a UK perspective on what constitutes stigma. This reduces comparability of our results with US applications but increases reliability in our UK context.

Conclusion

Findings of the first UK national survey of attitudes and beliefs about living with epilepsy suggest relatively low stigma among the sampled population. The subscale with the least stigma was negative stereotypes, suggesting that the average respondent disagreed or strongly disagreed with statements on negative stereotypes. Risk and safety concerns were associated with highest stigma. Attitude and knowledge of epilepsy significantly correlate, suggesting that improving public knowledge about epilepsy has potential to reduce stigma. The results from this project have potential to inform future work to improve awareness and understanding of epilepsy.

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436 **Table 1: Sociodemographic and experience characteristics of study sample**

Sociodemographic characteristics	
Age: Mean (SD)	49 (17)
Gender: N (%)	
Male	1,821 (47)
Female	2,040 (53)
Unknown (Other; Prefer not to say) *	14 (<1)
Ethnicity: N (%)**	
Asian or Asian British	189 (5)
Black or Black British	98 (3)
Chinese or Chinese British	33 (1)
British Mixed heritage	74 (2)
White	3,400 (88)
Unknown (Any other ethnic background; Prefer not to say)*	81 (2)
Employment: N (%)	
Employed	2107 (54)
Not in paid employment	1768 (46)
Education: N (%)	
Compulsory education	1240 (32)
Further education (i.e.. A-level, technical or professional qualification)	1332 (34)
Higher education (i.e. University degree)	1303 (34)
Have you ever been married or in a civil partnership: N (%)	
Yes	2,584 (67)
No	1,291 (33)
Do you have children: N (%)	
Yes	2,393 (62)
No	1,482 (38)
Household income: N (%)	
Low (under £19,999)	1,063 (27)
Medium (£20,000 - £39,999)	1,314 (34)
High (over £40,000)	1056 (27)
Unknown (Don't know; Prefer not to say)*	442 (11)
Do you consider yourself to have a disability or a long-term health condition: N (%)	
Yes	1,199 (31)
No	2,601 (67)
Prefer not to say *	75 (2)
Do you have epilepsy or a seizure condition: N (%)	
Yes	189 (5)
No	3686 (95)
Do you know someone with epilepsy or a seizure condition: N (%)	
Yes	1730 (45)
No	2,145 (55)
Have you ever witnessed a seizure?	
Yes	2,117 (55)
No	1,758 (45)

437 *Treated as missing in the regression analyses. ** The ethnic groupings used here are broad; there is
438 no breakdown of data for the more specific ethnic groups each contains. Some of the specific ethnic
439 groups have very different experiences to one another (https://guide.ethnicity-
440 factsfigures.service.gov.uk/a-z).
441

Table

Table 2: ABLE mean scores. Higher scores represent more negative attitudes (range 1 to 5)

ABLE subscale and items	Mean	Confidence interval (95%)	
ABLE Score (Chronbach alpha 0.94)	2.28	2.26	2.29
Risk and Safety (Chronbach alpha 0.85)	3.22	3.20	3.25
I would let my child ride in a car with a driver who has epilepsy	3.50	3.46	3.53
I would feel comfortable if my child rode in a car with a driver who has epilepsy	3.44	3.40	3.47
I would ride in a car if the driver has epilepsy	3.33	3.30	3.36
I would hire someone with epilepsy to babysit my infant child	3.23	3.20	3.27
I believe people with epilepsy can safely operate heavy machinery.	3.00	2.97	3.03
*I believe people with epilepsy should not drive, even if the DVLA allows them to get a driving license	2.84	2.80	2.87
Personal Fear and Social Avoidance (Chronbach alpha 0.90)	2.13	2.11	2.16
*I would be afraid to be alone with a person with epilepsy	2.57	2.54	2.61
*I would be nervous to be around a person with epilepsy because he or she might have a seizure	2.51	2.48	2.55
*I would NOT want my child to date someone with epilepsy	2.24	2.21	2.27
*I would avoid a person with epilepsy who has frequent seizures	2.16	2.13	2.20
*I believe being around a person with epilepsy would make me uncomfortable	2.09	2.06	2.12
*I would NOT go out again with a person I just started dating if I found out he or she has epilepsy	1.97	1.94	2.00
*I would NOT want to work with someone with epilepsy	1.85	1.82	1.88
*I would be embarrassed if someone in my family had epilepsy	1.67	1.63	1.70
Work and role expectations (Chronbach alpha 0.79)	2.07	2.05	2.09
*I believe there are many work activities people with epilepsy cannot do safely that I can do safely	2.84	2.80	2.87
I would expect just as much from people with epilepsy as from others	2.16	2.13	2.19
*I believe people with epilepsy cannot have as good quality of life as people without epilepsy	2.11	2.08	2.15
I believe people with epilepsy can do anything I can do	2.03	2.00	2.06
I believe people with epilepsy can work 40 hours per week	1.99	1.97	2.02
I believe people with epilepsy are able to cope with everyday life as well as other people	1.94	1.92	1.97
I believe people with epilepsy can lead normal lives	1.77	1.74	1.79
I believe people with epilepsy can be as successful at work as others	1.70	1.68	1.72
Negative stereotypes (Chronbach alpha 0.92)	1.67	1.65	1.69
*I believe people with epilepsy should NOT have biological children.	1.85	1.82	1.88
*I believe people with epilepsy have a mental health problem	1.85	1.82	1.88
*I believe people with epilepsy are unreliable.	1.81	1.78	1.84
*I believe people with epilepsy are NOT as smart as other people who do not have epilepsy.	1.61	1.58	1.64
*I believe people with epilepsy should NOT marry	1.58	1.55	1.61
*I would consider getting a divorce if my spouse were diagnosed with epilepsy.	1.54	1.51	1.57
*I believe people with epilepsy are possessed by a supernatural spirit.	1.45	1.43	1.48

*Item coded in reverse to match direction of underlying construct

Table 3: Results of knowledge questionnaire, and rank order of association between attitude score and lower knowledge of item (1= largest impact on stigma).

Knowledge item *(correct answer)*	Correct responses: n of 3875 (%)	ABLE score	Risk and safety	Fear and social	Work and role	Negative stereotypes
K13. You can catch epilepsy from someone who has it *(False)*	3,564 (92)	3		1	1	2
K15. All people with epilepsy have the same type of seizure *(False)*	3,507 (91)	1		3	3	1
K14. You can tell from looking at someone if they have epilepsy *(False)*	3,515 (91)	2		2	4	3
K10. With treatment, most people with epilepsy can go a year or more without a seizure *(True)*	3,431 (89)	4		4	7	4
K2. All people with epilepsy lose consciousness during seizures *(False)*	2,846, (73)	5	2	5	5	5
K4. For most people with epilepsy, seizures are well controlled with drug treatment *(True)*	3,492 (90)	6			2	
K11. There is a high likelihood of death every time a person with epilepsy has a seizure *(False)*	2,791 (72)	7	15		6	8
K12. Some seizures may last for a matter of seconds and may not be noticed by others *(True)*	3,477 (90)	9			8	6
K3. Some people get a warning or feeling shortly before a seizure*(True)*	3,337 (86)	10		6		7
K6. Anyone can develop epilepsy at any time *(True)*	2,629 (68)	11		8	9	
K7. When you see someone having a seizure, you should put some put something in the person's mouth to prevent the person from biting or swallowing their tongue *(False)*	1,778 (46)	8		7		10
K1. A seizure can be described as an abnormality in the function of the nerve cells in the brain *(True)*	3,543 (91)					
K8. Most people with epilepsy have seizures when looking at flashing lights *(False)*	1,811 (47)	12				
K9. People with epilepsy are protected by the Equality Act *(True)*	2,915 (75)					9
K5. For people with epilepsy, stress may cause some seizures *(True)*	3,444 (89)					
K16. Approximately how many people do you think are affected by epilepsy in UK *(1 in 100)**	1,404 (36)					

*Options were 1 in 10, 1 in 100, 1 in 1,000, 1 in 10,000. ***Note:*** In regression N=3368. Rank score = incorrect response associated with more negative attitude (1=greatest association). i.e. correct response associated with increased concern or more negative stereotypes. Blank cells = did not reach statistical significance i.e. there no associated with stigma in specified domain.

Table 4: Mean able scores of subgroups

	ABLE	Risk and safety concerns	Fear and social avoidance	Work and role expectations	Negative stereotypes
	Mean score (95% CI)	Mean score (95% CI)	Mean score (95% CI)	Mean score (95% CI)	Mean score (95% CI)
Male	2.32* (2.30-2.34)	3.18 (3.14-3.22)	2.22* (2.18-2.26)	2.1* (2.07-2.12)	1.75* (1.71-1.79)
Female	2.24* (2.22-2.26)	3.26 (3.22-3.29)	2.05* (2.02-2.09)	2.03* (2.01-2.07)	1.60* (1.57 - 1.62)
Employed	2.30(2.27-2.32)	3.14* (3.10-3.17)	2.17* (2.14-2.21)	2.07 (2.05-2.10)	1.76* (1.72-1.79)
Not in paid employment	2.25 (2.23-2.28)	3.33* (3.29-3.36)	2.08* (2.05-2.12)	2.06 (2.04-2.09)	1.57* (1.54-1.60)
Compulsory education	2.29 (2.26-2.31)	3.30 (3.26-3.35)	2.12 (2.08-2.17)	2.08 (2.04-2.11)	1.65 (1.16-1.69)
Further/higher education	2.27 (2.25-2.29)	3.19 (3.15-3.22)	2.14 (2.11-2.17)	2.06 (2.04-2.09)	1.68 (1.65-1.71)
Been in marriage or civil partnership	2.28 (2.27-2.30)	3.25* (3.223.29)	2.16* (2.132.19)	2.07 (2.05-2.10)	1.68 (1.65-1.71)
Never been in marriage or civil partnership	2.26 (2.23-2.29)	3.16* (3.11-3.20)	2.07* (2.03-2.11)	2.06 (2.02-2.09)	1.66 (1.61-1.70)
Have children – yes	2.27 (2.25-2.29)	3.27* (3.233.30)	2.14 (2.11-2.17)	2.06 (2.04 - 2.08)	1.66 (1.63-1.69)
Have children – no	2.28 (2.26-2.30)	3.15* (3.11-3.20)	2.12 (2.08-2.16)	2.08 (2.05-2.11)	1.69 (1.65-1.73)
Annual household income					
Low	2.29 (2.26-2.32)	3.03 (3.26-3.35)	2.11 (2.06-2.16)	2.10 (2.07-2.14)	1.64 (1.60-1.68)
Medium	2.26 (2.24-2.29)	3.22 (3.18- 3.26)	2.12 (2.07-2.16)	2.06 (2.03-2.09)	1.65 (1.61-1.69)
High	2.30 (2.27-2.34)	3.12 (3.07-3.17)	2.21 (2.16- 2.27)	2.06 (2.02-2.09)	1.78 (1.72-1.84)
Person with epilepsy – yes	2.51* (2.42-2.60)	2.86 * (2.74-2.98)	2.53* (2.09-2.14)	2.18 (2.09-2.27)	2.43* (2.24-2.62)
Person with epilepsy – no	2.7 * (2.25-2.28)	3.24 * (3.22-3.27)	2.11* (2.36-2.70)	2.06 (2.04-2.08)	1.63* (1.61-1.65)
Know someone with epilepsy* - yes	2.14* (2.19-2.24)	3.29 * (3.25-3.32)	2.23* (2.20-2.26)	2.10 * (2.07-2.12)	1.68 1.64-1.71)
Know someone with epilepsy* - no	2.33* (2.31-2.35)	3.14* (3.10-3.18)	2.01* (1.98-2.05)	2.03* (2.00-2.06)	1.66 (1.62-1.70)
Has witnessed a seizure - yes	2.25* (2.23-2.27)	3.19 (3.16-3.23)	2.08* (2.04-2.11)	2.05 (2.03 -2.07)	1.70 (1.66-1.74)
Never witnessed a seizure	2.31* (2.29-2.33)	3.26 (3.22-3.30)	2.20* (2.16-2.23)	2.09 (2.063-2.12)	1.63 (1.60-1.67)

**Significant result at p<0.001*

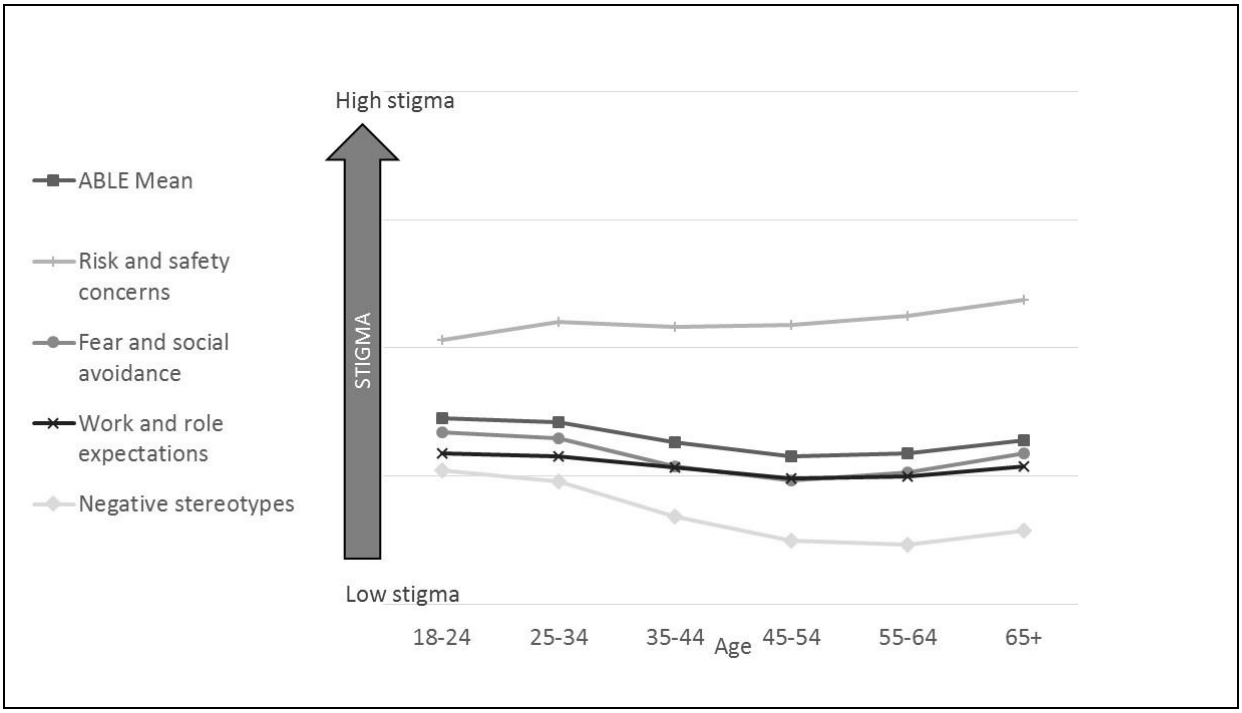
***Other than self.*

Table 5: Regression models

	ABLE score	Risk and safety concerns	Fear and social avoidance	Work and role expectations	Negative stereotypes
Sociodemographic factors					
Age: base category = 45-54 years					
18-24 years	0.0897	-0.0407	0.102	0.00956	0.151*
25-34 years	0.0810	0.0629	0.068	0.0141	0.119
35-44 years	0.0391	0.00549	0.0196	0.0354	0.04
55-64 years	0.0475	0.0517	0.102	0.0438	0.014
65 years +	0.134*	0.117	0.263*	0.0893	0.132*
Gender: male	0.0636*	-0.0794	0.0996*	0.0572	0.136*
Ethnicity: base category = white					
Asian	0.0700	0.0107	0.0984	0.0037	0.093
Black	0.0281	0.0979	-0.0467	0.102	-0.0365
Chinese	0.0951	0.177	0.142	0.0143	0.0696
Mixed	-0.00269	-0.122	-0.0313	-0.0134	0.0345
Employment: in employment	0.00851	-0.0955	0.0653	-0.0154	0.0559
Education: further/higher	0.00453	-0.0269	0.0337	0.0198	0.0151
Marriage/civil partnership	0.0323	0.0243	0.0542	0.0351	0.0605
Children	-0.002	0.0795	0.0109	-0.0203	-0.0237
Household income: lower	-0.0216	-0.0537	0.012	-0.0593	-0.0063
R^2 (stage 1)	***0.088***	***0.032***	***0.073***	***0.034***	***0.143***
Experience factors					
Has epilepsy	-0.00882	-0.345*	0.0845	-0.112	0.330**
Knows someone with epilepsy	-0.105*	-0.113*	-0.199*	-0.0517	-0.0674*
Has witnessed a seizure	-0.0542*	0.00825	-0.109*	-0.0366	0.00497
R^2 (stage 2)	***0.112***	***0.046***	***0.108***	***0.039***	***0.180***
Knowledge factors *(see table 6 for full wording)*					
k1:abnormality of the function of the brain	0.0486	0.0487	0.0860	0.0644	-0.019
k2: people lose consciousness during a seizure	-0.167*	-0.155*	-0.204*	-0.139*	-0.214*
k3: some people get a warning before a seizure	-0.0868*	0.00166	-0.147*	-0.0584	-0.123*
k4: for most seizures are well controlled …	-0.118*	-0.101	-0.108	-0.164*	-0.117
k5: stress may cause some seizures	-0.00717	0.0747	-0.0386	0.0191	-0.0787
k6: anyone can develop epilepsy…	-0.0742*	-0.0919	-0.0883*	-0.0920*	-0.0419
k7: put something in the person's mouth	-0.0921*	-0.0448	-0.137*	-0.0620	-0.0770*
k8: have seizures when looking at flashing lights	-0.0497*	-0.0801	-0.0412	-0.031	-0.0358
k9: protected by the Equality Act	-0.0517	-0.000693	-0.0547	-0.0660	-0.0810*
k10: with treatment most people can …	-0.173*	-0.0785	-0.269*	-0.130*	-0.233*
k11: high likelihood of death every time a person …	-0.112*	-0.149*	-0.0890	-0.137*	-0.116*
k12: seizures may last for a matter of seconds …	-0.0886*	0.0366	-0.0783	-0.109*	-0.153*
k13: you can catch epilepsy …	-0.216*	0.216	-0.404*	-0.180*	-0.510*
k14: you can tell by looking at someone …	-0.217*	0.169	-0.383*	-0.151*	-0.488*
k15: all people have same type of seizure …	-0.235*	0.160	-0.378*	-0.161*	-0.523*
k16: Prevalence of epilepsy in the UK	0.025	0.00013	0.0404	0.00568	0.0623
R^2 (stage 3)	**0.354**	**0.082**	**0.309**	**0.179**	**0.481**
Other unobserved factors					
_cons	3.564*	3.158*	3.955*	3.187*	3.865*
Model statistics					
N	3368	3368	3368	3368	3368
R-sq	0.354	0.082	0.309	0.179	0.481
adj. R-sq	0.348	0.073	0.302	0.171	0.476
rmse	0.413	0.797	0.683	0.526	0.58

*Significant result at $p \leq 0.01$

Figure 1: Attitude by age groups



Supplementary material 1: ABLE item responses

Percentage of respondents who agreed with each statement, in order of worst to best: n of 3785 (%)

	Strongly disagree 1	2	3	4	Strongly Agree 5
I believe I know a lot about epilepsy	796 (21%)	1,408 (36%)	915 (24%)	586 (15%)	170 (4%)
I would let my child ride in a car with a driver who has epilepsy	893 (23%)	1,054 (27%)	1,199 (31%)	552 (14%)	177 (5%)
I would feel comfortable if my child rode in a car with a driver who has epilepsy	785 (20%)	1,046 (27%)	1,291 (33%)	588 (15%)	165 (4%)
I believe people being treated for epilepsy can have a seizure at any time*	83 (2%)	489 (13%)	1,380 (36%)	1,530 (39%)	393 (10%)
I would ride in a car if the driver has epilepsy	664 (17%)	1,008 (26%)	1,308 (34%)	731 (19%)	164 (4%)
I would hire someone with epilepsy to baby-sit my infant child	503 (13%)	908 (23%)	1,620 (42%)	683 (18%)	161 (4%)
I believe seizures in people with epilepsy require emergency medical assistance*	145 (4%)	1,045 (27%)	1,334 (34%)	1,033 (27%)	318 (8%)
I believe people with epilepsy can safely operate heavy machinery	296 (8%)	801 (21%)	1,644 (42%)	885 (23%)	249 (6%)
I believe I feel sorry for people who have epilepsy*	601 (16%)	1,024 (26%)	865 (22%)	1,122 (29%)	263 (7%)
I believe there are many work activities people with epilepsy cannot do safely that I can do safely*	444 (11%)	965 (25%)	1,446 (37%)	816 (21%)	204 (5%)
I believe people with epilepsy should not drive, even if the DVLA allows them to get a driving license*	498 (13%)	1,019 (26%)	1,287 (33%)	760 (20%)	311 (8%)
I would be worried that a seizure could happen at any time if I were around a person with epilepsy*	467 (12%)	1,267 (33%)	823 (21%)	1,075 (28%)	243 (6%)
I would feel comfortable if my child were in primary school class in which the teacher has epilepsy	204 (5%)	599 (15%)	1,377 (36%)	1,327 (34%)	358 (10%)
I would be afraid to be alone with a person with epilepsy*	749 (19%)	1,358 (35%)	772 (20%)	792 (20%)	204 (5%)
I would be nervous to be around a person with epilepsy because he or she might have a seizure*	730 (19%)	1,543 (40%)	673 (17%)	750 (19%)	179 (5%)
I believe I am prepared to help a person with epilepsy who is having a seizure	181 (5%)	407 (11%)	774 (20%)	1,712 (44%)	801 (21%)
I believe if people with epilepsy have seizures, it is because they are not doing what their doctor tells them to do*	1,011 (26%)	1,469 (38%)	918 (24%)	346 (9%)	131 (3%)

I would NOT want my child to date someone with epilepsy*	1,024 (26%)	1,460 (38%)	955 (25%)	302 (8%)	134 (3%)
I believe people with epilepsy should NOT be primary school teachers*	1,061 (27%)	1,472 (38%)	855 (22%)	369 (10%)	118 (3%)
I would avoid a person with epilepsy who has frequent seizures*	1,225 (32%)	1,423 (37%)	719 (19%)	392 (10%)	116 (3%)
I would expect just as much from people with epilepsy as from others	55 (1%)	269 (7%)	702 (18%)	2,065 (53%)	784 (20%)
I believe people with epilepsy have trouble managing their day to day activities*	1,209 (31%)	1,505 (39%)	753 (19%)	321 (8%)	87 (2%)
I believe people with epilepsy cannot have as good quality of life as people without epilepsy*	1,286 (33%)	1,461 (38%)	654 (17%)	348 (9%)	126 (3%)
I believe being around a person with epilepsy would make me uncomfortable*	1,254 (32%)	1,566 (40%)	605 (16%)	345 (9%)	105 (3%)
I believe people with epilepsy should NOT do many recreational activities that I am able to do*	1,338 (35%)	1,594 (41%)	543 (14%)	278 (7%)	122 (3%)
I believe people with epilepsy can do anything I can do	65 (2%)	254 (7%)	468 (12%)	2,031 (52%)	1,057 (27%)
I believe people with epilepsy can work 40 hours per week	78 (2%)	140 (4%)	597 (15%)	1,925 (50%)	1,135 (29%)
I would NOT go out again with a person I just started dating if I found out he or she has epilepsy*	1,528 (39%)	1,318 (34%)	736 (19%)	197 (5%)	96 (2%)
I believe people with epilepsy are able to cope with everyday life as well as other people	60 (2%)	157 (4%)	492 (13%)	1,963 (51%)	1,203 (31%)
I believe parents should expect less of their child if the child has epilepsy*	1,492 (39%)	1,560 (40%)	466 (12%)	268 (7%)	89 (2%)
I believe people with epilepsy have a mental health problem*	1,820 (47%)	1,239 (32%)	483 (12%)	235 (6%)	98 (3%)
I would NOT want to work with someone with epilepsy*	1,675 (43%)	1,462 (38%)	477 (12%)	173 (4%)	88 (2%)
I believe people with epilepsy should NOT have biological children*	1,716 (44%)	1,395 (36%)	500 (13%)	174 (4%)	90 (2%)
I believe children with epilepsy can perform well in mainstream schools (not a special needs school)	30 (1%)	103 (3%)	432 (11%)	1,855 (48%)	1,455 (38%)
I believe people with epilepsy are unreliable*	1,722 (44%)	1,507 (39%)	389 (10%)	169 (4%)	88 (2%)
I believe people with epilepsy should tell their employers that they have epilepsy	49 (1%)	96 (2%)	403 (10%)	1,814 (47%)	1,513 (39%)
I believe people with epilepsy can lead normal lives	30 (1%)	99 (3%)	358 (9%)	1,836 (47%)	1,552 (40%)
I believe people with epilepsy should hide their condition from others except for close family and friends*	1,982 (51%)	1,233 (32%)	394 (10%)	195 (5%)	71 (2%)
I believe having epilepsy is nothing to be embarrassed about	92 (2%)	93 (2%)	255 (7%)	1,641 (42%)	1,794 (46%)

I believe people with epilepsy can be as successful at work as others	37 (1%)	62 (2%)	248 (6%)	1,884 (49%)	1,644 (42%)
I would be embarrassed if someone in my family had epilepsy*	2,172 (56%)	1,192 (31%)	244 (6%)	171 (4%)	96 (2%)
I believe having epilepsy is nothing to be ashamed about	54 (1%)	98 (3%)	222 (6%)	1,533 (40%)	1,968 (51%)
I believe people with epilepsy are NOT as smart as other people who do not have epilepsy*	2,342 (60%)	1,030 (27%)	264 (7%)	150 (4%)	89 (2%)
I believe people with epilepsy should NOT marry*	2,405 (62%)	993 (26%)	253 (7%)	152 (4%)	72 (2%)
I would consider getting a divorce if my spouse were diagnosed with epilepsy*	2,518 (65%)	898 (23%)	262 (7%)	127 (3%)	70 (2%)
I believe people with epilepsy are possessed by a supernatural spirit*	2,872 (74%)	542 (14%)	225 (6%)	174 (4%)	62 (2%)

*During analysis. item coded in reverse to match direction of underlying construct